



Washington State Developmental Disabilities Council



2007 National Core Indicators Review Panel Report



Introduction

The Developmental Disabilities Council convened a panel of self-advocates, family members of persons with developmental disabilities (DD) and service providers to review the results of two Core Indicators surveys conducted in Washington State during 2005-2006. The Core Indicators is a national study that assesses performance and outcome indicators for state developmental disabilities service systems.

Washington State Core Indicators survey participants were selected from the caseload of the Division of Developmental Disabilities (DDD).

The workgroup met three times during September and October 2007. The two survey results reviewed by the committee were:

Surveys Reviewed

Adult Family Survey (AFS) A random survey mailed to families with an adult family member with DD living in their family home who received at least one service or support from DDD besides case management.

Family Guardian Survey (FGS) A random survey mailed to families with an adult family member with DD living outside of the family home or legal guardians. The family member needed to receive service coordination and at least one additional “direct” service or support from DDD to be selected for the survey.

Using the data from the surveys, the workgroup developed systems change recommendations for presentation to the Developmental Disabilities Council and the Division of Developmental Disabilities. The workgroup made recommendations in all five sub-domains of the survey.

Five Survey Areas

- Information and planning
- Access to and delivery of services and supports
- Choices and control
- Community connections
- Outcomes and satisfaction with services and supports

In each area, there are recommendations, and a workgroup composite score for each recommendation. Recommendations were ranked (using values identified by the group) on a scale of 1-5, with 5 being a rating of highest importance. Each recommendation includes reference to the supporting data as well as additional input received from workgroup members.

For ease in reading, survey names are abbreviated in the text of the report while detailed information about the surveys and the workgroup members are provided in Appendix B.

Overview

The 2007 Core Indicators Review Panel worked to develop 21 recommendations for the Division of Developmental Disabilities and the Washington State Developmental Disabilities Council. The Panel's recommendations include concrete Ideas for Action whenever possible.

While reviewing the material, the Panel also identified some positive things they saw in the data. Highlights of what they saw included:

- 90.6% of respondents stated that the staff that helped them with planning are generally respectful and courteous (always or usually). (Question 8) (AFS)
- High numbers of people report that they are able to get support workers or translators who speak their language, when English is not their first language. 88.2% of respondents reported they were able to always, usually, or sometimes able to have this. (Question 18) (AFS)
- 91.3% of respondents stated that their support staff are always or usually respectful and courteous. (Question 26) (AFS)
- Washington is doing a lot better than average for family members reporting they have control over the hiring and management of their support workers. 53.5% of Washington respondents stated they or their family member have control and/or input over the hiring and management of their support workers, versus the state score average of 36.3%. (Question 30) (AFS)
- 94.2 % of people report that the services and supports they receive through the Division have made a positive difference (always, usually or sometimes) in the life of their family. (Question 41) (AFS)
- There was also a marked difference in community connections, with individuals with developmental disabilities living out of the family home having more access to community connections than those living in their family home.

“Things coming out lower can say sometime positive about the way things are changing.

People are starting to know they have choices and can have a voice.

They may feel safe enough to say when they don't like something.”

- Panel Member

The Review Panels recommendations begin on page 4.

Information and Planning

Recommendation 1	<i>We recommend the Division reinforce the importance of including individuals with developmental disabilities as the primary focus in the planning process, along with family members or others of their choosing. (Score: 4.69)</i>
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Discussion	The panel noted a bias towards asking family members about their satisfaction with the planning process as opposed to asking the individual with developmental disabilities' satisfaction with the process. The slanting of questions toward family members can reinforce the idea that individuals with developmental disabilities aren't capable of participating in the planning process for their own services.
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Supporting Data	<p>Only 50% of families say that the staff who assist them with planning help them figure out what they need as a family to support their family member (Question 6) (AFS)</p> <p>The number of families who report that their family member's service plan includes things that are important to them is 66%. However 24.6% report this happens only sometimes. 9.3% say seldom or never. (Question 5) (FGS)</p>
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Ideas for Action	<p>The Division can work with the Core Indicators Survey staff to more directly capture the voice of the individual with developmental disabilities in the survey questions.</p> <p>The Division can work to ensure that its own planning processes put the voice of the individual with developmental disabilities receiving services first.</p>
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Recommendation 2	<i>We recommend that the Division and the DDC make adequate information available to individuals with developmental disabilities and their families so that they have enough information to participate in planning. (Score: 4.4)</i>
Discussion	<p>While family members report that they feel involved in their family member's service plan, most feel that they don't have enough information to participate in that planning.</p> <p>There is a (real or perceived) lack of connection between the different parts of the system (Birth to 3, schools, employment training, adult services) that makes it especially difficult to believe there is enough information for individuals with developmental disabilities and their families to have a complete picture of the available options. The current system is also highly dependent on the knowledge and availability of DDD case managers.</p>
Supporting Data	<p>Washington scored lowest in families getting enough information to participate in planning. (Question 3) (AFS)</p> <p>People feel involved even if they don't have the information – 75.5% of families say that they have helped to develop their family member's service plan. (Question 4) (AFS)</p> <p>The number of families who report that their family member's service plan include things that are important to them is 66%. (Question 5) (FGS)</p>
Ideas for Action	<p>The Division could contact states/counties that scored high in this area and learn what they are doing to get needed information to individuals with developmental disabilities & their families.</p> <p>The Division can work to make information available outside of the agency. The Informing Families/Building Trust project is one example of how the Division can contract to provide information to individuals with DD and their families independent of a DDD case manager.</p>

Recommendation 3	<i>We recommend the Division and DDC continue to improve access to information about available services and make sure that the information provided is easy to understand. (Score: 4.3)</i>
Discussion	<p>There is a large gap between Washington state and other states in this area. A large number of respondents are unable to understand the information they receive from the Division. Currently some families report fear around receiving information from the Division, because information from the Division is usually bad news. While information numbers are low, there has been a slight improvement over the 2002 and 2004 surveys.</p> <p>The current system is highly dependent on case managers for both information and resources. There is a perception that case managers are “gate keepers” in both of these areas. Additionally, information availability is inconsistent throughout the state.</p> <p>There is concern that the new DDD assessment may add complexity to an already hard-to-understand system.</p>
Supporting Data	<p>Washington scored lower in families getting enough information to plan (Question 3) (AFS)</p> <p>Only 50% of families say that the staff who assist them with planning help them figure out what they need as a family to support their family member. (Question 6, AFS)</p>
Ideas for Action	<i>See “Ideas for Action” under Recommendation 2</i>

Access to and Delivery of Services and Supports

Recommendation 4	<i>We recommend the Division, Home and Community Services (HCS) and the Health Care Quality Authority (HCQA) look at the protocols in place to provide adequate quality assurance across settings. (Score: 5.0)</i>
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Discussion	We need quality assurance for all the systems which providing Medicaid Personal Care services for individuals with developmental disabilities, including transportation and other generic resources.
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Ideas for Action	The Division, HCS and HCQA work collaboratively to address quality assurance cutting across systems providing MPC services.
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Recommendation 5	<i>We recommend the Division create a system which proactively prevents emergent situations and improve its 24 hour/7 day a week response to individuals with disabilities and families when emergent situations occur. (Score: 4.91)</i>
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Discussion	<p>Emergency help from the Division is only available during standard operating hours (8:00 am to 5:00 pm, Monday through Friday, excluding holidays). Other states have 24 hour help when crisis occurs. There is a sense of frustration because the Division's response to crisis is slow and inconsistent across the state.</p> <p>More importantly, the Division needs to structure a system that will provide services which will prevent emergent situations from occurring.</p>
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Supporting Data	Only 50% of people in Washington always or usually get help when they need emergency help. Around 1/3 of respondents state that they seldom or never get services and supports they need in an emergency or crisis right away. (Question 17) (AFS)
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Ideas for Action	Look at states that already have 24 hour emergency help, find what will work for Washington and implement.
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Recommendation 6	<i>We recommend the Division create specific policies in regards to what constitutes an “emergency situation” and develop specific (timely) procedures to follow when an individual with developmental disabilities and their family is in an emergency situation. (Score: 4.83)</i>
Discussion	In reviewing the survey data, it was unclear what constituted an emergency and who defined it. The Division needs to clarify (with input from individuals with DD and their families) what constitutes an emergency and develop standardized procedures for responding in a crisis.
Ideas for Action	Develop with stakeholders (individuals with DD, their family members and service providers) a definition of an emergency and procedures to follow when an emergency occurs.
Recommendation 7	<i>We recommend the Division make a new assessment of the competencies and skills required for its case management positions and design a new system based on these that will (1) Respond to the needs of people now and (2) incorporate advances in information technology. (Score: 4.0)</i>
Discussion	The skills and competencies needed to be an effective case manager have changed significantly. A comprehensive revision of these would ensure that individuals filling case manager positions have skills which more closely match the current position requirements.
Supporting Data	Only 50.6% of respondents say that the staff who assist them with planning always or usually help them figure out what they need as a family to support their family member. (Question 6) (AFS) Only 34.0% of respondents stated they always or usually receive information about the services and supports available to their family.(Question1) (AFS)
Ideas for Action	Revise case manager skills and competencies.

Recommendation 8	<i>The Division needs to continue to improve training of case managers to better ensure that consistent information about services is provided to all individuals with developmental disabilities and their families. (Score: 3.9)</i>
Discussion	DDD can't keep piling more and more duties onto case managers without assessing the impact on workload and capacity. However, consistent information is a problem and information varies to families obtaining needed services.
Supporting Data	<p>Only 50.6% of respondents say that the staff who assist them with planning always or usually help them figure out what they need as a family to support their family member. (Question 6) (AFS)</p> <p>Only 34.0% of respondents stated they always or usually receive information about the services and supports available to their family.</p>
Recommendation 9	<i>The Division, in collaboration with University Centers for Excellence in Developmental Disabilities (UCEDD) and others, needs to facilitate access to the resources for special equipment, assistive technology or accommodations that individuals with developmental disabilities need. (Score: 3.9)</i>
Discussion	There is assistive technology and information out there, but lack of marketing is an issue. It is hard to access these resources without knowing about them.
Supporting Data	Only 59.4% of respondents stated they always or usually have access to the special equipment or accommodations that their family member needs. (Question 20) (AFS)
Ideas for Action	<p>This could be done by developing or contracting for this specialized need (access to assistive technology) and training case managers how to use them and connect individuals to these resources.</p> <p>Additional marketing of assistive technology resources.</p>

Choice and Control

Recommendation 10 ***We recommend increased choice and control of services for persons with developmental disabilities. (Score: 4.0)***

Discussion The figures from Washington state are higher than many of the states surveyed for choice and control over support workers. The numbers are less high in regards to agencies.

Supporting Data 21.3% of family members report they seldom or never get a choice about the agencies or providers that work with their family. (Questions 27) (AFS)

Washington is doing a lot better than average for family members reporting they have control over the hiring and management of their support workers. (Questions 30 and 31). (AFS)

Ideas for Action Continue to work toward providing choices for individuals with developmental disabilities and their families in all service areas.

Recommendation 11 ***We recommend the Division work with individuals with developmental disabilities, families, and providers to clarify the parameters of choice and control of service providers. (Score: 3.45)***

Discussion In some instances providers who are employers are put in legal dilemmas when responsibilities as an employer conflict with the individual with developmental disabilities' desire to have control over their support workers.

Supporting Data 21.3% of family members report they seldom or never get a choice about the agencies or providers that work with their family. (Questions 27) (AFS)

Washington is doing a lot better than average for family members reporting they have control over the hiring and management of their support workers. (Questions 30 and 31).

(Recommendation 11) Ideas for Action	Provide written information for families regarding parameters of provider choice. Create a DVD similar to the “Fair Hearing” or “Complaint Process” that can be given to families both by DDD case managers and community service providers that explains what choices are available to individuals with developmental disabilities and their family members.
Recommendation 12	<i>We recommend the Division be responsible for providing information to individuals with developmental disabilities and their families about how money is being spent (by the Division) on behalf of the individual with developmental disabilities. (Score: 3.08)</i>
Discussion	A majority of the family members surveyed reported they didn’t know how much was spent by DDD on behalf of their family member with a developmental disability. When families want to know what is spent, they may turn to their service provider to find out what services cost. Providers then feel they need to justify the price/cost of the services they provide.
Supporting Data	Overwhelming majority (69.2%) of family members don’t know how much money is spent by the Division on behalf of their family member with a developmental disability. (Question 32) (AFS) There was a low percentage (21.3%) of family members who knew how much money was spent by the Developmental Disabilities agency on behalf of their family member. (Question 32) (AFS)
Ideas for Action	Along with the service provision statement provide an accounting of the specific service provisions and the cost the Division is incurring to provide those services.

Community Connections

Recommendation 13 ***We recommend the Division work to identify what barriers are keeping individuals with developmental disabilities from participating in community activities and work to help individuals with developmental disabilities, families and communities address them. (Score:4.6)***

Discussion	The high numbers of respondents stating that their family member with a developmental disability seldom or never has access to community activities is disturbing. This question also doesn't address what barriers are keeping individuals with developmental disabilities from participating in their communities.
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Supporting Data	<p>19.7% of individuals report that their family member seldom or never <u>has access</u> to community activities. (Question 36) (AFS). Individuals living in out-of home placement actually had greater access to community activities. 9.4% of the FGS participants reported that their family member seldom or never participated in community activities.</p> <p>Individuals who report that their family member seldom or never participates in community activities is 37.3%. (Question 37) (AFS). The FGS survey showed a lower number of participants who seldom or never participate in community activities (24.1%)</p>
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Ideas for Action	<p>Possible ideas: Contract with others for this, have lists, use local community resources such as recreation centers, parent to parent, etc.</p> <p>Add a question to the Core Indicators Survey that asks respondents to identify what barriers are standing in the way of their family member's ability to participate in community activities.</p>
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Recommendation 14	<i>We recommend the Division work to help individuals with developmental disabilities use family, friends or neighbors for support needs when they desire. (Score:4.2)</i>
Discussion	Using family, friends or neighbors for support needs not only builds on the idea of natural supports, but may also increase individuals with developmental disabilities sense of community inclusion.
Supporting Data	People aren't getting help from staff to use family, friends and neighbors as support for family needs. 47% of those in the AFS reported they seldom or never are helped to use family, friends and neighbors to provide supports. (AFS) (Question 35)
Ideas for Action	See "Ideas for Action" under Recommendation 15
Recommendation 15	<i>We recommend the Division actively work toward helping individuals with developmental disabilities and their family members use ordinary supports in their community that everyone else uses. (4.1)</i>
Discussion	Being disconnected from a support system that the general community uses could increase the sense of isolation individuals with developmental disabilities and their family members experience. Using ordinary supports in the community can also increase communities' awareness of individuals with developmental disabilities and break-down stereotypes.
Supporting Data	A majority of respondents (52.5%) report that the staff that help them plan or provide support seldom or never help them use typical supports in their community. (Question 34) (AFS) The number of individuals who report that the staff that help them plan seldom or never helps them to connect to typical supports in their community is too high. (Question 21) (FGS)

Ideas for Action	<p>DDD should explore/pilot efforts to increase communities' abilities to be more welcoming and inclusive of people with developmental disabilities.</p> <p>Establish support and secure funding (outside the area of employment) that would result in an individual with developmental disabilities gaining skills and opportunities to be more independent and live a more meaningful life of their choosing.</p>
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Outcomes and Satisfaction Recommendations

Recommendation 16 ***We recommend the Division's Grievance Procedure be clearly explained to both the person with developmental disabilities and their family members. (Score:3.9)***

Discussion Complaint process needs to be clearer. Goes back to the communication piece.

Supporting Data Too many people don't know the process for filing a grievance (46.5%). (Question 39) (AFS)
Number of individuals who aren't familiar with the grievance process is too high (43.9%) (Question 26) (FGS)

Ideas for Action Recommend the Division continue to make fund and distribute the DDD Complaint (Grievance) Process DVD
Continue training case managers on the importance of explaining the DDD Grievance Process in easy to understand language.

Recommendation 17 ***We recommend that the Division work with the Core Indicators Project staff to identify a more objective measurement of client's happiness and satisfaction. (Score: 2.3)***

Discussion This question was seen as ambiguous as the definition of happiness is left to the respondent and the respondent is giving a response for someone else. There is some value in what is behind the question, namely, the well-being of the individual with developmental disabilities. There are quality of life questions that could provide a more objective idea of well-being.

The panel also thought it would be interesting to compare "quality of life" for those who have jobs versus no- jobs, differences between regions, home versus out of home living arrangements, as well as access to services such as transportation.

Supporting Data	Only 80.4% of respondents state that their family member is always or usually happy. (Question 29) (FGS)
Ideas for change	The Division of Developmental Disabilities Core Indicators staff could work with Human Services Research Institute (HSRI) staff to identify more objective indicators of happiness questions for future Core Indicator surveys..

Demographics/Measurement Processes

Recommendation 18 ***We recommend the Division continue to work toward capturing the voice of individuals with developmental disabilities in these surveys by conducting face-to-face interviews of individuals with developmental disabilities (by an independent third party) about the services they receive and want to receive.(Score:4.3)***

Discussion While we commend the Division's participation in the Core Indicator's Project, it is important that the individual with developmental disabilities be asked directly about the services they receive whenever possible. It is also important to recognize that having DD staff members conducting these interviews can skew the responses the Division gets to survey questions. Individuals with developmental disabilities may not have the assertiveness to tell someone from the Division that they are not happy with services they are receiving.

Supporting Data Both the Adult Family Survey and the Family Guardian Survey are dependent on the responses of the individuals with developmental disabilities' family members.

Ideas for Action Conduct face-to-face interviews for individuals with developmental disabilities about the services they receive and ideas they have for improving those services.

Recommendation 19 ***We recommend that the Division work with the Core Indicators Project staff to be able to identify whether respondents are from rural or urban areas. (Score: 3.8)***

Discussion The project could add a question to the questionnaire that asks if the individual with a developmental disability lives in a rural or urban area. An additional question that might be helpful would be whether the individual with developmental disabilities is on a waiver..

Supporting Data	Survey shows that Washington's state's income level is high, but panel members wondered if the results were skewed and what the income levels look like if King, Pierce and Snohomish counties were taken out of the equation. (AFS)
Ideas for Action	DDD CI staff meet with the CI project staff to add this question to the CI survey. If that is not possible, Washington could add this as a question on the Washington state survey.
Recommendation 20	<i>We recommend that UCEDD (U of W) initiate a study on the differences in access to quality healthcare reported in the Core Indicators study and what's anecdotal in regard to access to health care services and determine what may explain these discrepancies.(Score: 3.75)</i>
Discussion	Data received from other health care access reports points to difficulty in accessing health care for the general population and higher difficulty for those who have medical coupons (Medicaid). The numbers cited in the Core Indicators study indicate that high numbers of respondents had access to medical and dental care as well as prescriptions.
Supporting Data	<p>88.6% of respondents in the AFS survey stated their family member with a developmental disability always or usually had access to health care. (Question 21) (AFS)</p> <p>94.0% of respondents in the AFS survey stated their family member with a developmental disability always or usually had access to necessary medications (Question 23) (AFS)</p> <p>77.7% of respondents in the AFS survey stated their family member with a developmental disability always or usually had access to dental services. (Question 22) (AFS)</p>
Ideas for Action	UCEDD study this discrepancy in data and determine what is responsible for these differing results.

Recommendation 21	<i>We recommend the Division work with the Core Indicators Project staff to identify the usefulness of asking surveyed families the level of mental retardation of their family member with a developmental disability. (Score: 2.8)</i>
Discussion	The panel was wondering why the studied asked about the level of mental retardation of the person with a developmental disability, especially since a sizeable percentage of family members were unable to answer the question.
Supporting Data	<p>13.7% of people in the AFS didn't know the level of mental retardation of their family member (Table 9) (AFS)</p> <p>18.0% of people in the FGS didn't know the level of mental retardation of their family member (Table 9) (AFS)</p>
Ideas for Action	Washington state CI staff meet with CI project staff to identify the usefulness of this question and to advocate for omission of this question if no useful purpose is served by the inclusion of the question.

Appendix A: Demographic Comparison

The percentage of families with household incomes of \$25,000 or less is significantly higher (over two times higher) than levels reported for the state population in the 2000 census.

<i>Survey Household income</i>	2007 AFS	WA- US Census
		2000
Below \$15,000	17.2 %	8.0%
\$15,001-\$25,000	20.2%	9.1%
\$25,001-\$50,000	35.5%	28.4%
\$50,001-\$75,000	16.7 %	24.5%
Over \$75,000	10.3%	30.1%

The ethnic composition of the surveyed populations is roughly similar to the state's population. One significant difference is that the white population in the FGS survey is much higher than the census levels and the number of Hispanic, Asians and mixed race is lower.

<i>Race Ethnicity of Individual with DD (%)</i>	2007 AFS	2007 FGS	WA -US- Census
			2000
White	83.3%	91.8%	81.8%
Black	2.9%	2.8%	3.2%
Asian	4.9%	1.6%	5.5%
American Indian/Alaska Native	2.9%	2.2	1.6
Hawaiian/Pacific Islander	.7%	.2%	.4%
Mixed race	4.7%	.8%	3.6%
Other/Unknown	.9%	.3%	3.9%
Hispanic/Latino	4.5%	1.6%	7.5%

Appendix B: Core Indicator Studies Reviewed & Panel Members

In making its recommendations, the Core Indicators Panel reviewed:

- **The Family Guardian Survey Report** (April 2007). Available online at: http://www.hsri.org/docs/786_P8_FGS_05_06_final.pdf
- **The Adult Family Survey Report** (April 2007). Available online at: http://www.hsri.org/docs/786_P8_AFS_05_06_final.pdf

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